



**Special  
Needs  
Information  
Point**

**Annual  
Report  
2003 - 2004**



Maybe if SNIP were *just* a Special Needs Information Point handing out leaflets and advice, money wouldn't be such an issue. It could toddle quietly along filling a gap in the market. But SNIP, as you all know, is so much more than that. As a body, it is not a passive *giver* of information, SNIP...or more to the point, the people who are SNIP...actively seeks to offer real support, practical help and guidance and, crucially, hope for a better future to children with special needs and their families.

Snip has, and continues to, create the market...to reach out to families and professionals who maybe didn't even know that there was a better way, a better life.

Let me use this message to say a quick 'hello' to all and to appeal to those of you who might be in a position to offer financial help.

Any funding that comes SNIP's way is not about keeping an organisation afloat, it will make a direct and dramatic impact on the lives of vulnerable young people who need and deserve a helping hand.

I thank you in advance .

*Kaye Adams*

**Kaye Adams**

## Project Manager's Introduction



Shirley Young

Welcome to the Snip Annual Report for 2003-04. I cannot believe how the project has grown since I joined as part time Information co-ordinator in 1992.

I thought I was doing well in those days dealing with 30 enquiries per month. This financial year ended with our busiest month ever - no fewer than 266 families benefited directly or indirectly from the tremendous wealth of knowledge, experience and expertise built up by the organisation over the past twelve years!

It is a huge privilege to be involved in families lives and my staff and I never underestimate the courage it can take to lift the telephone and call a number, not knowing who is at the other end of the phone and bare your soul. I am therefore delighted with the new Snip parents video which means that people can see the office and some of the staff beforehand. Having it available in community languages as well as a British Sign Language version means that we are able to reach parents who are even further marginalised. We are very grateful to Elaine C Smith for fronting our fundraising video that we intend to use to promote Give As You Earn to prospective donors. I am also very proud of the way Snip

continues to enable parents of children with special needs not only to benefit from its services or to volunteer with the organisation, but to be employed. Our policies on flexible working which take account of the complex, complicated and often very challenging lives we live mean that the majority of the staff are also parents of disabled children. They bring with them a wide range of professional skills as well as their experience as parents.

Our challenge, as ever, is not just about service delivery, but about ensuring the continuity of funding for the service. The Celebrity Millionaire money was a huge boost, and the development of our training service is a great income-generator, but our long-term future still relies on finding additional sources of funding. Over the coming year I will therefore be spending an increasing amount of my time on this vital aspect of my role.

### Shirley Young



Elaine C Smith

Snip is a voluntary organisation based at the Royal Hospital for Sick Children in Edinburgh. It is managed by a committee of parents of children/young people with special needs and professionals working in the field.

## Snip aims to:

- Promote information to families and carers of children with special needs, the children and young people themselves and the professionals who work with them
- Provide emotional support to parents/carers
- Educate professionals in the statutory and voluntary sector about the needs of families of children and young people who have chronic illness or are disabled
- Link with other information and support services in the statutory and voluntary sector, making and receiving referrals as appropriate
- Raise the profile of the needs of disabled children and their families in the wider community
- Provide input into policy at local and national level with regard to children and young people with special needs

These aims translate into three distinct areas of work for Snip, which result in many positive outcomes for children with special needs and their families:

## Information, Advice and Support

As information and support workers our roles are divided into 2 main areas of work:

- **Information and Advice**
- **Giving Emotional Support**

Both of these aspects of our work are carried out either face to face in our office, on the wards of the hospital or via our Parents' Support Line. As a result of our involvement parents tell us:

*"Without Snip I would not have felt able to apply for DLA. Thanks for all your help."*

This year Snip enabled families to claim around £100,000 in benefits and £1,630 from Trust Funds and Charities

*"I have been waiting for a bus pass form for my son for 5 years. It took one phone call to your office on Friday and I now have a form – many thanks."*

At Snip we understand the need to make information "live". Many parents feel that when they receive information from others it is just given to them without enough explanation for them to be able to do anything with it.

## A professional told us:

*"A considerable amount of effort clearly goes into sustaining your service and providing some very useful information for parents of children with special needs."*

The advice and guidance we give to parents is on what steps to take and why the need to take them. We can draw on our own experiences to advise parents on how to access services for their child, to work with the numerous professionals involved with the child's care, what questions to ask etc.

*"I have found the service most helpful - the only place I believe can really answer your questions. The information that was sent to me was very helpful - thank you."*

We give parents advice on options that they have and make them aware of the different choices that are open to them. Every situation is different and every call we receive, even from the same person, is usually about something else that is happening in their life. Professionals also use the service and come back to us with different questions relating to the wide range of families that they are working with.

*"I am a health visitor and have used Snip's services on numerous occasions for families on my caseload. I have always found the information you give to be very relevant and up to date. I also know that parents I have spoken to feel the same way."*

*"Excellent service, very welcoming staff, I was stressed not knowing where to turn. Staff helped me ease this."*

*"I was so touched by the helper on the phone as she took time to listen to my query and was patient and I really felt that she went out of her way to help with my query."*

## Website

The website received a major overhaul at the beginning of 2003 so that it complied with all the major international standards for accessibility. The Quentin Blake "Bird brain" drawing was adopted as a motif for the website.

Another major change was the submission of the Snip website to all the major search engines for indexing. Unless a site is indexed by these, anyone doing a general web search would be unlikely to come across it. The website was also accepted for inclusion by a number of online directories.

It is our intention that all Snip publications should ultimately be available for download

from the website, and we are well on the way to achieving this. Our leaflets for parents and professionals as well as the annual report and monthly newsletters are all now available for download. Additionally, a number of factsheets were developed during 2003 - topics available so far include "Autistic spectrum disorder" and "Asperger's syndrome." These are proving to be very popular downloads.

Other agencies (including the Scottish Executive) are recommending our website as a valuable resource, which all helps to increase usage and awareness of Snip.

## Statistics

Between April 2003 and March 2004, we had over 7000 visitors to the website. Email enquiries have also risen steadily over the first quarter of 2004, making up 5% of all enquiries received.

## Information for Children and Young People



David & Shirley at Award Presentation

This is an area we hope to develop further over the next few years. This year we were delighted to receive a National Information Forum award for our **Young Person's Leaflet**, which we developed in partnership with a group of young disabled people from a club in Edinburgh.

Snip staff travelled to London to collect the award with representatives from the club, including one of the young people - David. David had never been to London before and he thoroughly enjoyed his day - in particular the journey from the airport to City Hall by limousine!

*Our comic, 'Kidzone', is now being produced by a young disabled person.*

## Emotional Support

The number of parents accessing emotional support from Snip has risen dramatically over the last year. We take the time to listen to what parents are saying and try never to be judgemental. We give parents the space and acknowledgement that it is not always easy to tell complete strangers how you are feeling...

*"They take time to get information from you. Also, I have a speech problem, and they waited until I was ready."*

We give parents the opportunity to be heard and listen to them when sometimes they are at their most vulnerable and feel that no one understands and that their life is not worth living.

*"Thank you all so much for your never-ending understanding, patience and time. You have all been so wonderful and caring with me. It means a lot to know you all are only a phone call away from me. A great big thank you from the bottom of my heart. Keep up all the fantastic work you do."*

Waiting on appointments to see professionals can some time take a long time due to waiting lists and parents can feel very isolated and useless, as they are unable to help their child. This can cause feelings of anger and frustration.

*"I have been waiting for around 6 months for a meeting with \*\*\*\*\*. After talking with Claire for 30 minutes, she has answered all my questions and more - a fantastic service."*

## Counselling and Therapeutic Support Groups

Sometimes parents need more than emotional support and Snip can offer 1:1 counselling or Therapeutic Support groups for such parents who live in Edinburgh and Midlothian. We use an independent, fully trained and accredited counsellor for these services to keep them separate from our information functions.

In March we held a day at the Engine Shed giving parents the chance to try out, for free, a range of complementary therapies such as massage and Reiki. It was also a chance for them to meet the counsellor and hear more about what she can offer. Feedback from the parents who attended was very good and we intend to repeat this event in the future.

### Special Needs Information Point



### Therapeutic Support Groups and Counselling

Do you have a child or young person with an illness, disability or special need?

Would you like the chance to talk confidentially about your feelings either in a group setting or 1:1 with a counsellor?

## Education and Training

A key development for Snip over the last year has been the development of its training role, The aim of which is threefold :

- First and foremost to improve the service families receive from the professionals who work with them
- Secondly to support the professional development of those working with families
- Thirdly to provide an income to support other aspects of the service

### Sessions have included -

- Emotional implications of caring for a child/young person with special needs
- Impact of childhood disability on family functioning
- Including children with specific conditions into after school clubs
- Breaking bad news
- Childhood Disability equality
- Communicating with families

Participants have ranged from junior doctors to hospital consultants, out-of-school-care staff to senior Educational Psychologists. Some of the feedback we have received in evaluations is as follows:

*“I really enjoyed the workshop and the style of presentation - very straight, informative and easy to listen to. I appreciated the trainer’s honesty as well.”*

*“This is a very valuable and worthwhile workshop for professionals. It is very useful to hear about real experiences and to recognise the importance of reflecting on your practice.”*

## Key Worker Training

The City of Edinburgh Council has used some of its Changing Children’s Services Fund money to commission Snip to train professionals to become ‘key workers’ for families of children with special needs as part of the move to a ‘care co-ordination’ approach.

The ‘first wave’ of courses ran from May 2003 through to February 2004. The course covers two and a half days. Over one hundred and fifty professionals took part in the courses and in February 2004 an ‘awareness’ day was held for managers. The training course was also delivered in Fife to participants that included a number of parents.

The objectives for the training are -

- To emphasise the importance of developing self awareness in the role of Key worker
- The identification and promotion of attitudes, values and skills needed for effective working
- To stress the need for regular reflection and review of practice
- To encourage ongoing professional development

### Evaluation

Participants on each course were asked to complete an evaluation form, which was collected from them at the end of the three days. In December the evaluations were sent to an external evaluator - Gail Peterson at the Royal Bank of Scotland - for analysis.

She reported that overall, 98% of respondents gave a response of average, very good or excellent (mainly very good/excellent) with only 2% giving a less than average mark. There were many positive comments from the respondents regarding the courses and trainers including the following -

*"Well prepared, structured and executed"*

*"Hearing about actual situations/personal experiences was very effective and invaluable"*

*"One of the best training courses I've ever been on"*

## Programme for 2004 - 2005

Snip has successfully applied for continued funding to deliver Key Worker training through to 2006. Six 3 day courses will be delivered in 2004 - 5 plus three 1 day 'refresher' courses that will focus on specific issues such as the development of chairing skills. There will also be another awareness day for managers and six workshops on childhood disability awareness

## Consultation and Policy

This year, as usual, Snip has been at the forefront of promoting improvement in the way families of children with special needs are treated in Scotland:

### Care Co-ordination and keyworking

Shirley's involvement in the Care Co-ordination Network UK as a Trustee and part of the Scotland steering group has kept her very busy. She helped organise a successful practitioners day in Stirling in October attended by around 40 people from all over Scotland who came together to share good practice in supporting families through a more co-ordinated approach to the delivery of services.

The steering group has since secured funding from the Scottish Executive to employ a development worker who will promote and support the development of

better co-ordination of services for disabled children and their families throughout Scotland.

An important part of this role will be:

to ensure that children and young people themselves, as well as their parents, influence how care co-ordination and keyworking develop in their area. The steering group will now become an advisory group to the worker and Snip is delighted to be involved in this.

At a more local level, Shirley has been leading a multi-agency Action Team as part of the Lothian Universities NHS Trust's Community and Therapies Re-design project. As a result more than 40 families in parts of Edinburgh, East and Midlothian are now benefiting from a care co-ordinated approach and have an allocated keyworker. This number will increase over the next few months as the approach is rolled out. A Care Co-ordination Facilitator has now been appointed to support the work and the action team will end once the initial monitoring and evaluation of the approach has been established.

### Education

Snip continues to influence national policy development in this area with Shirley being invited by Peter Peacock to sit on the advisory group to the Additional Support for Learning Bill Implementation Team. The Bill heralds the biggest changes to the way support is provided to disabled children in 20 years and Snip is delighted that Shirley is able to take her experience of having two disabled young people and her understanding of the complexities of this issue through her work with parents over the past twelve years to the team.

Locally Shirley is also part of the City of Edinburgh Special Educational Needs Forum.

## Social Work

Snip is represented on the Strategy Development Group sub-group for disabled children for the City of Edinburgh Council and provides valuable parental input into this planning body. This group also oversees the projects for disabled children funded through the Changing Children's Services Fund.

Snip staff also provide input into the following:

- Scottish Accessible Information Forum
- Children in Scotland Special Needs Advisory Group
- Cerebral Palsy Register for Scotland



SNIP Committee and members of staff

## SNIP Staff Team Listing

The current Snip staff team are -

Shirley Young: Project Manager - Parent

Claire Edwards: Information & Training Manager - Parent

Sharon Dunlop: Information & Support Worker - Parent

Veronica Warrington: Information & Support Worker - Parent

Helen Edmond: Information Worker

Margaret Barclay: Parent Volunteer

## Committee Profile

The AGM in October saw the retirement of Miranda Harvey as Chair after six years of service, including a stint as Treasurer. Sue McLean also stood down at the end of her term of office as Treasurer. We are extremely grateful to them both for their hard work and commitment over the years and both she and Miranda received tokens of appreciation.

Rachel Wilson, Vice Chair, stepped in as interim Chair for one year and Shona Moyes was appointed as Treasurer. Three new committee members joined, making the line up as follows:

Chair: Rachel Wilson - Parent

Treasurer: Shona Moyes - Parent

Secretary: Louise Jarman - Professional  
Joy Blakeney - Professional  
Lesley Mount - Parent/  
Professional  
Gail Peterson - Parent  
Marlene Snodgrass - Parent  
Jillian Allatt - Parent/  
Professional

## Treasurer's Report

This year we have used Fundraising Consultants to help generate income from Trust Funds and have re-established a fundraising sub-committee to develop a three year fundraising strategy. This is very important for the continued success of Snip as the wonderful "Celebrity Who wants to be a millionaire?" money won and donated so generously by our patron Kaye Adams and her friend Ross Kelly is fast being used up. As expected after the success of last years conference there has been an increase in Snip s income from the delivery of Key Worker Training for Dumfries & Galloway, West Lothian Healthcare, City of Edinburgh Council, Lothian University Hospital NHS Trust and Fife Council. This has also been reflected in requests for us to carry out commissioned work, speaker s fees and delivery of other training programmes. (As the majority of the conference fees were outstanding at last years financial year end they will show in this year's account). Increased training activity and the trip to London to collect the National Information Forum award led to higher than usual staff travel expenditure this year.

This year we have been able to extend our "Therapeutic Support Groups", due to continued support from the City of Edinburgh Council and Midlothian Council, which we know has been a real "lifeline" for some parents and carers.

Our thanks go to the Royal Hospital for Sick Children for their continuing support by providing us with our fully accessible office and for covering our telephone and postal costs. Due to our increase in staff numbers they have also very kindly provided separate office space for Shirley Young, our Project Manager.

We also continue to receive support from the City of Edinburgh Council and Midlothian

Council. Our final payment from the Community Fund, for 2002 - 2003 was received in this financial year.

We give special thanks to Ian Rankin who so very generously continues to support SNIP along with the regulars at the Swany's and Oxford Bars, the BP Harding Committee, the Scottish Cry-sis Society, the Margaret Black Trust, the Russell Trust and to everyone who raised or donated money including our G.A.Y.E donators.

We are very grateful to have been supported by friends and members this year with the continued success of our annual ceilidh and raffle, the book signing Ian Rankin carried out at the RHSC street fair and our wonderful Santa letters.

The SNIP office would be delighted to hear from anyone who would be interested in contributing to the work of SNIP or in becoming involved in our Fundraising sub-committee. Our aims for the coming year are:

- Secure Trust Fund donations to contribute to Parents' Support Line and youth work costs
- Increase Give as You Earn Donations
- Increase spread of collecting cans
- Develop more fundraising events and projects such as a Snip Car Boot Sale, Christmas card etc
- Encourage existing donors to give on a more regular basis
- Target more local authorities
- Continue to extend income generation through training

**Shona Moyes**

# ACCOUNTS SUMMARY

## Accounts Summary Year Ended 31 March 2004

	Unrestricted Funds £	Restricted Funds £	Total Funds £	Total Funds 2003 £
Income	62,706	24,185	86,891	95,270
Expenditure	114,423	35,159	149,582	107,884
Fund balances 31/3/03	127,398	10,974	138,372	150,986
Fund balances 31/3/04	75,681	-	75,681	138,372

### How SNIP spends its money

Fundraising costs	4%
Cost to carry out the work of SNIP	94%
Management & administrative costs	2%

This report should be read in conjunction with the annual independently examined accounts which are available on request from SNIP office.

**Special Needs Information Point**  
**Royal Hospital for Sick Children**  
**14 Rillbank Terrace**  
**Edinburgh EH9 1LN**  
**Helpline/ Fax 0131 536 0583 (10am - 4pm Mon to Fri)**  
**Office/ Text phone/ Fax: 0131 536 0360**  
**E-mail: [snip@btinternet.com](mailto:snip@btinternet.com)**  
**Web-site: [www.snipinfo.org](http://www.snipinfo.org)**

**Scottish Charity No: SC000264**

## **Agents, Advisors and Supporters**

**Bankers:** Royal Bank of Scotland, University Branch, 61 Forrest Road, Edinburgh  
**Payroll Advisors:** SCVO  
**Independent Examiner:** James Anderson & Co. Chartered Accountants  
**Collating Team:** Pepperbank Co-operative

